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of Veterans Affairs

# Patient Generated Health Data: Best Practices in the Integration into Clinical Care

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# Presenters



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# Learning Objectives

**At the conclusion of this training session, VA staff should be able to:**

- Be familiar with common definitions of health technologies and components of patient-generated health data (PGHD).
- Describe the benefits of using PGHD in clinical care.
- Demonstrate how PGHD can support clinical management and decision making in a model of continuous care.





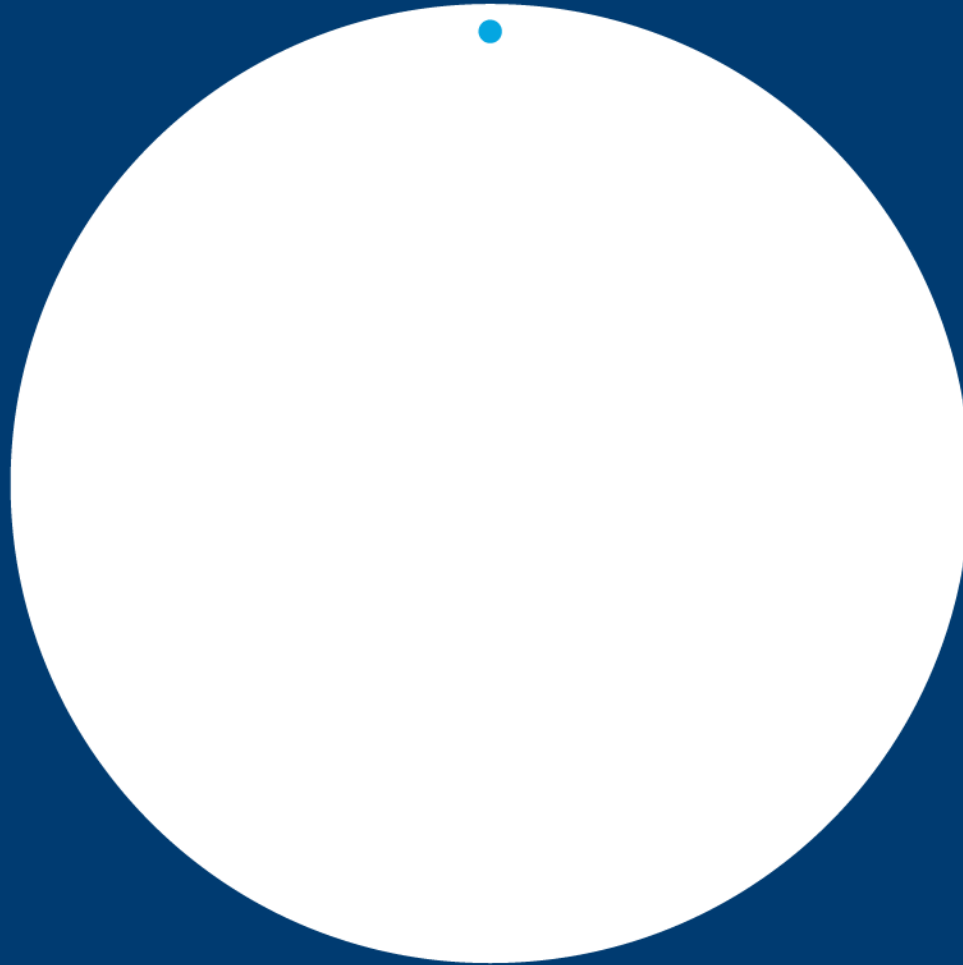
# Agenda

- Introduction: Leveraging the 'White Space'
- What is Patient Generated Health Data (PGHD)?
- Use and Benefits of PGHD
- What VA Staff Need to Know About PGHD



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# Leveraging the “White Space”



**525,600 minutes**

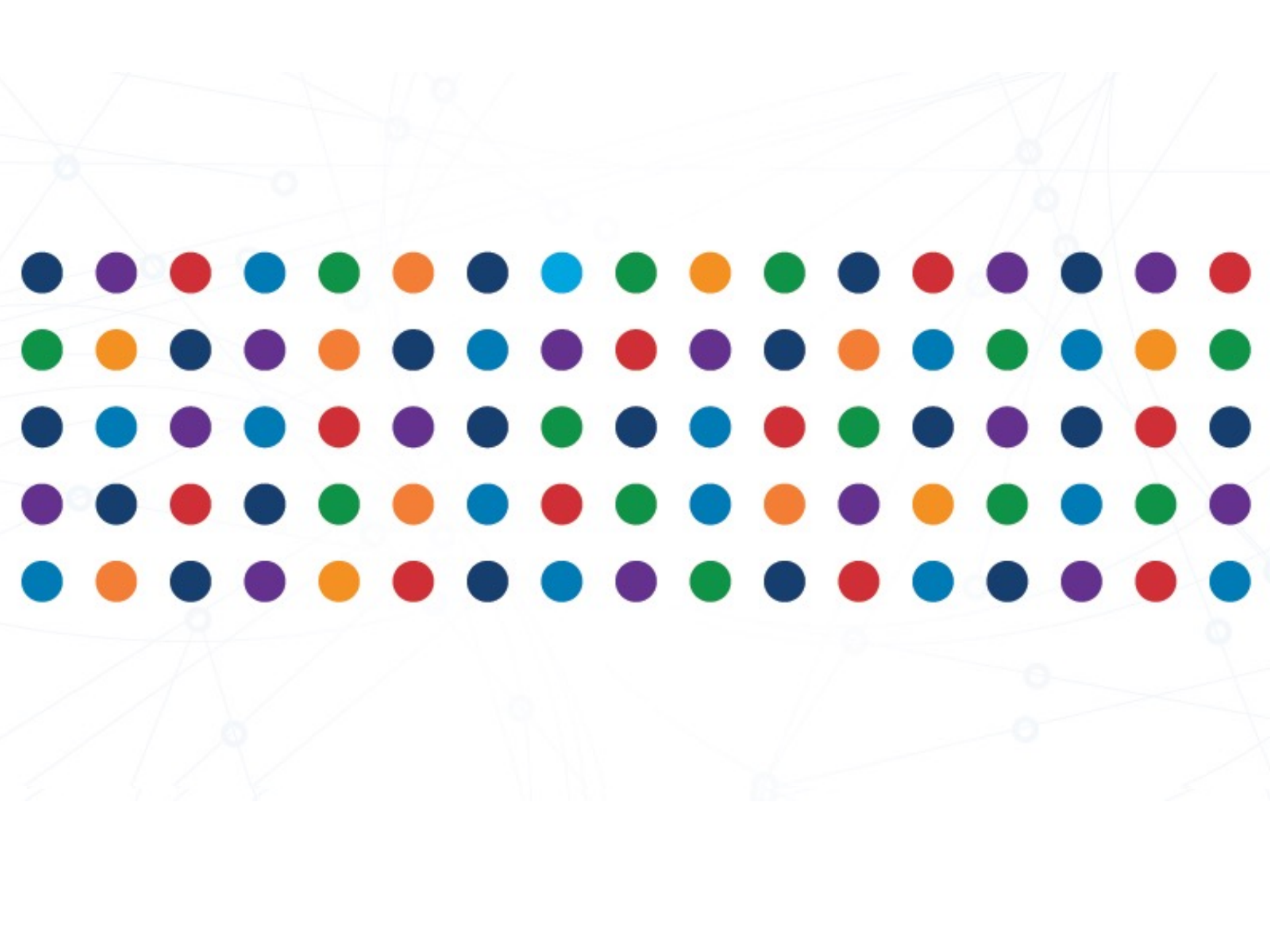


# LTG Horoho on “The White Space”



<https://www.youtube.com/watch?v=Lft0yDVH2tA>







EHR Data informs  
Episodic Care



EHR + PGHD informs  
Comprehensive and  
personalized Care





Pen and paper



# Digital Tools



# VA Health Apps





# What is Patient-Generated Health Data?



Vital signs



Lifestyle data



Quality of life data



Other health data



# How is PGHD Collected?

Patient-generated health data (PGHD) is health-related data created, recorded, or gathered by patients, their family members, or caregivers.

- Patients capture and record PGHD. Data is captured through clinical apps, wearable devices, devices such as glucometers, or input from patients.
- PGHD is usually distinct from the data generated in clinical settings and through encounters with clinicians.
- Patients decide whether to share the data with providers.





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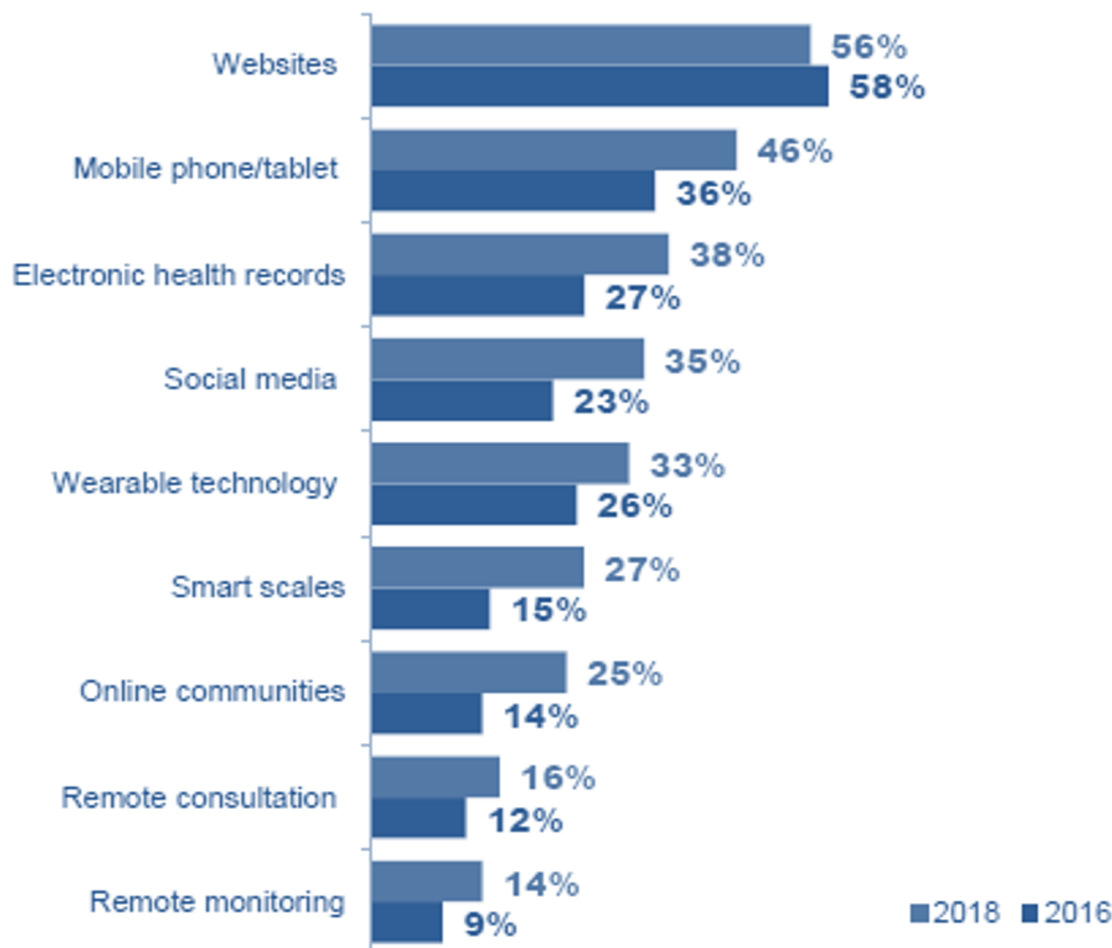
# Use and Benefits of PGHD





# What health technologies do people use?

## TECHNOLOGIES USED TO MANAGE HEALTH



(Consumer Survey on Digital Health: US Results, 2018; N=2,301)



# Worldwide Use of Sensors and Wearables

- 325 million (Piwek et al. 2016) and estimated to increase to 929 million by 2021 (Statistica, 2018)
- Increasingly used as the primary assessment and/or treatment modality (Hermens & Vollenbroek-Hutton 2008; Hilty et al. 2021; Kvedar et al. 2014).



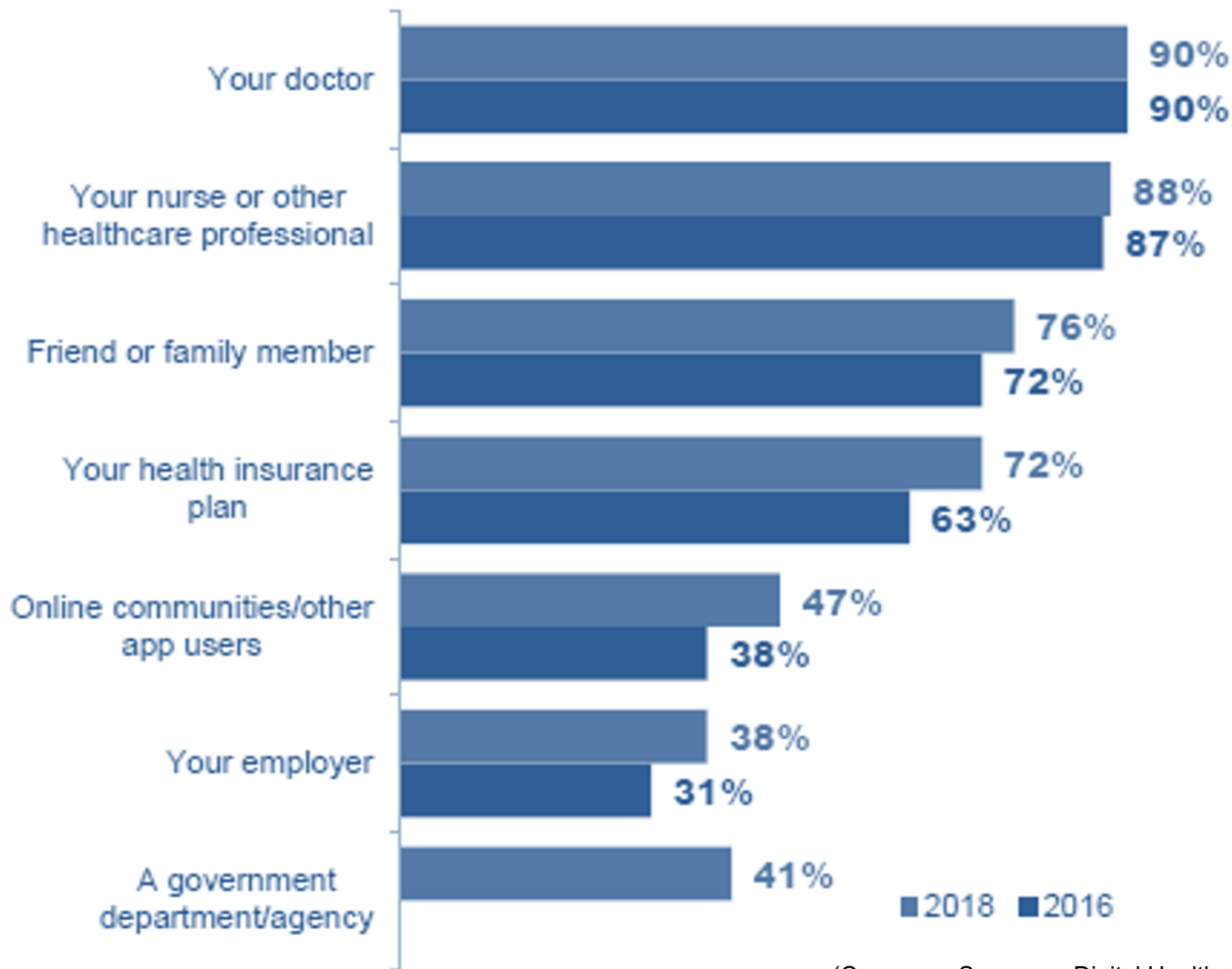


# Sensors and Wearables Transforming Care

- Transition from a cross-sectional, manual transfer of data at a healthcare appointment to a 24 × 7, longitudinal framework (Areàn et al. 2016; Luxton 2016; Torous and Roberts 2017; Ariga et al. 2019).
- Makes the collection, processing, and sharing of data more integrated and provides the opportunity for real-time feedback based on the ecology (home, health, lifestyle, social) of patients in natural settings (Seko et al. 2014).
- These data support “in-time” clinical decision support (Rohani et al. 2018; CDS) (Greenes et al. 2018) and automatic monitoring systems (Garcia-Ceja et al. 2018; National Academy of Sciences, Engineering and Medicine 2020).



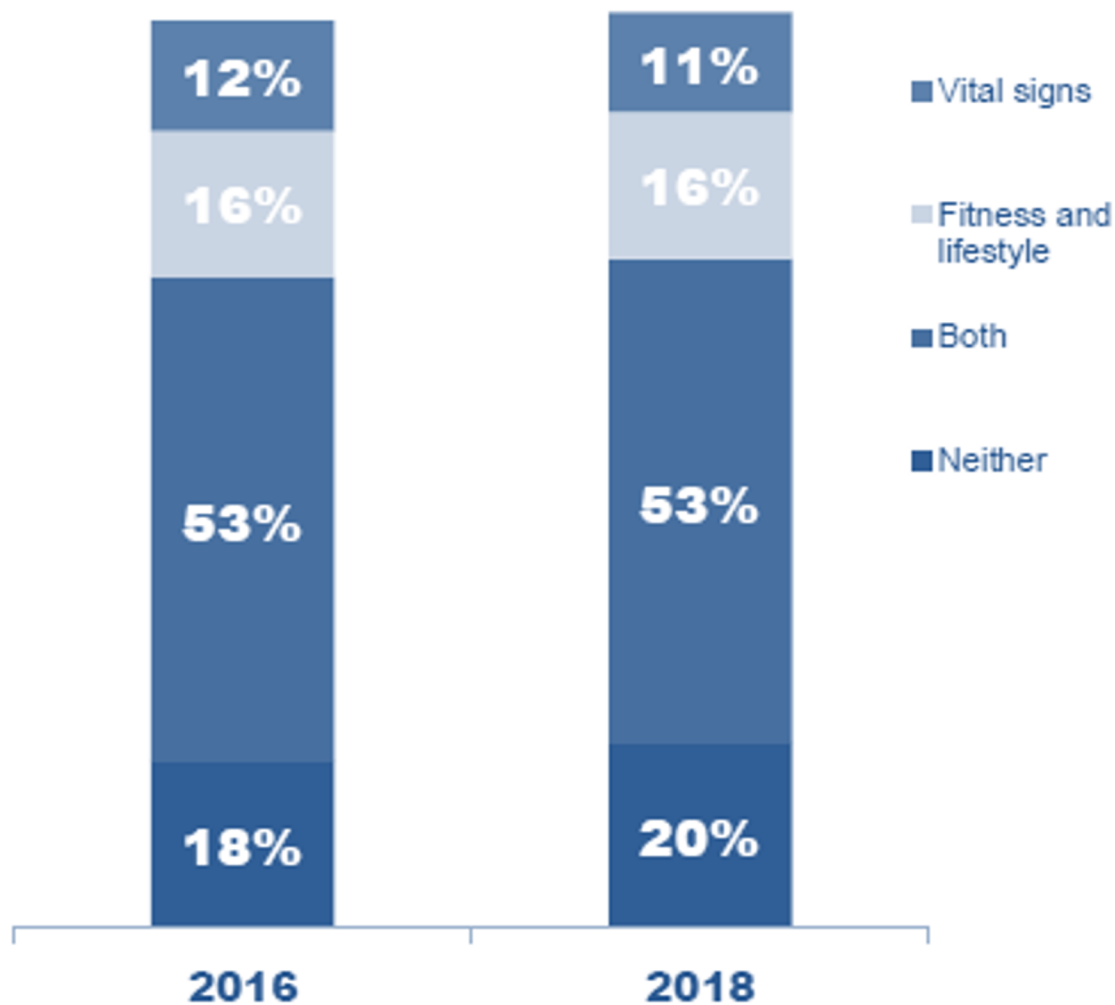
# Who do you want to share wearable data with?



(Consumer Survey on Digital Health: US Results, 2018; N=2,301)



# What wearable data are people willing to share?



(Consumer Survey on Digital Health: US Results, 2018; N=2,301)



# Veteran Benefits of PGHD

- Empowers Veterans by gaining a greater understanding of health and wellness.
- Provides supplementary information to help Veterans and their care teams make health care decisions together.
- Veterans control their PGHD and decide whether to share this data with their care teams.





# Patient Attitudes Toward Use of PGHD

**75%** understanding your health condition

**73%** engaging in your own health

**73%** monitoring the health of a loved one

**69%** improves overall quality of care

**69%** patient/physician communication

**69%** accuracy of the medical record

**66%** patient satisfaction



(Consumer Survey on Digital Health: US Results, 2018; N=2,301)





# Healthcare Staff Benefits of PGHD

- Leverage the 'white space'
- Augment their understanding of patients' health and wellness
- Support clinical decision-making and delivery of care
- Identify meaningful trends that can explain or predict health-related outcomes





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# What VA Staff Need to Know About PGHD



# Agreement for PGHD Use

If the provider requests that the patient collect and share PGHD, or if a patient begins sharing PGHD with VA, that provider should discuss how PGHD will be viewed and acted upon with the patient.

- Set expectations for patient sharing and provider viewing PGHD, and for care decisions to be made.
- Inform the patient that it is their responsibility to make the VA provider aware of situations in which the patient believes that they may be experiencing a medical issue or need medical attention based on their PGHD.
- Document any agreement regarding the collection, monitoring and use of PGHD in a note within the patient's EHR.





# Accessing and Documenting PGHD

- PGHD is stored in a secure VA database.
- Providers can access PGHD through Virtual Care Manager.
- PGHD is not considered a part of the patient's official medical record unless the provider actively adds the data to the Electronic Health Record (EHR).





# Key Take-Aways

- Patient-generated health data (PGHD) helps both Veterans and providers gain a greater understanding of patient health and wellness.
- While PGHD does not replace standard medical care, it can provide supplementary information to help Veterans and their care teams make health care decisions together.
- Patients are primarily responsible for capturing and recording PGHD, and for deciding whether to share this data with their care teams.
- It is the responsibility of VA providers to inform patients about how they intend to use PGHD in care.





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# Questions



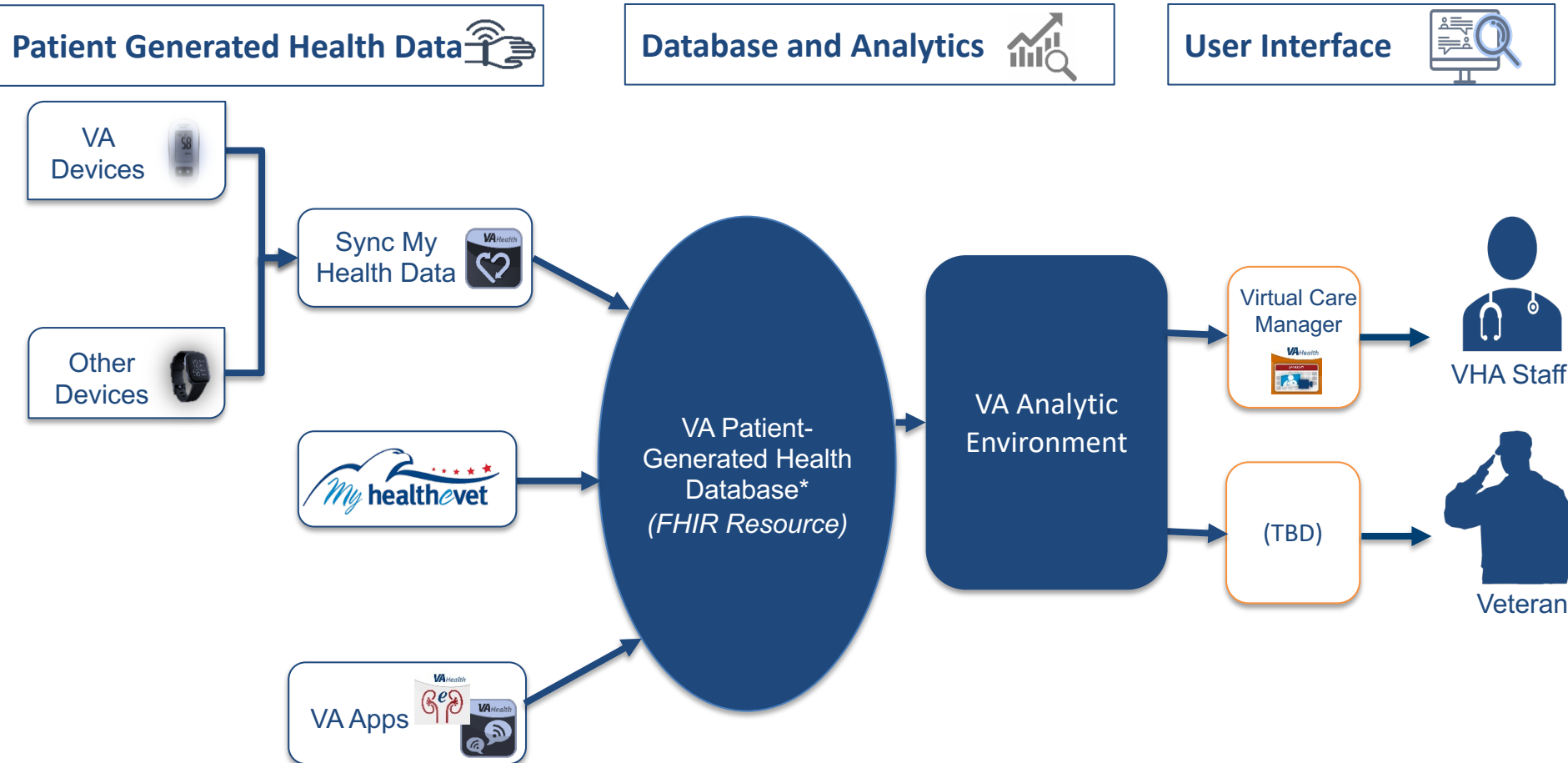
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# Backup





# PGHD Sources and Data Flow



\*Veteran chooses which data goes into the PGH Database



# VA PGHD Policy

Department of Veterans Affairs  
Veterans Health Administration  
Washington, DC 20420

VHA DIRECTIVE 6506  
Transmittal Sheet  
(DATE)

## REVIEW AND USE OF PATIENT-GENERATED HEALTH DATA UNDER THE OFFICE OF CONNECTED CARE

**1. REASON FOR ISSUE:** This Veterans Health Administration (VHA) directive establishes policy and responsibilities for Department of Veterans Affairs (VA) staff who have access to review and use patient-generated health data (PGHD) submitted by Veterans through the Office of Connected Care (OCC) mobile health applications.

**2. SUMMARY OF CONTENT:** This directive:

- a. Defines PGHD that is submitted by Veterans and stored in OCC's PGHD database and provides background on how it is collected, accessed and used, and by whom.
- b. Establishes expectations for how providers will communicate with Veterans about PGHD.
- c. Describes provider responsibility for documenting any agreed upon plans, as were agreed to by the Veteran, for access and use of PGHD.

**3. RELATED ISSUES:** VA Handbook 6300.5, Procedures for Establishing and Maintaining Privacy Act Systems of Records, dated August 3, 2017; VHA Directive 1200, Research and Development Program, dated May 13, 2016; VHA Directive 1200.01, Research and Development Committee, dated January 24, 2019; VHA Directive 1605.01, Privacy and Release of Information, dated August 31, 2016; VHA Directive 1605.02, Minimum Necessary Standard for Access, Use, Disclosure and Requests for Protected Health Information, dated April 4, 2019; VHA Directive 1058.03, Assurance of Protection for Human Subjects in Research, dated September 17, 2020; VHA Directive 1200.05(1), Requirements for the Protection of Human Subjects in Research, dated January 7, 2019; VHA Handbook 1200.12, Use of Data and Data Repositories in VHA Research, dated March 9, 2009; VHA Handbook 1907.01, Health Information Management and Health Records, dated March 19, 2015; and Assistant Secretary for Information and Technology and Chief Information Officer Memorandum, "Ethical Principles for Access to and Use of Veteran Data," dated June 24, 2020.

**4. RESPONSIBLE OFFICE:** The Office of Connected Care (12CC) is responsible for the content of this directive. Questions may be addressed to [VHA12CCCConnectedCareAction@va.gov](mailto:VHA12CCCConnectedCareAction@va.gov).

**5. RESCISSIONS:** None.

**6. RECERTIFICATION:** This VHA directive is scheduled for recertification on or before the last working day of [DATE]. This VHA directive will continue to serve as national VHA policy until it is recertified or rescinded.



# Understanding Data Flow and Data Security

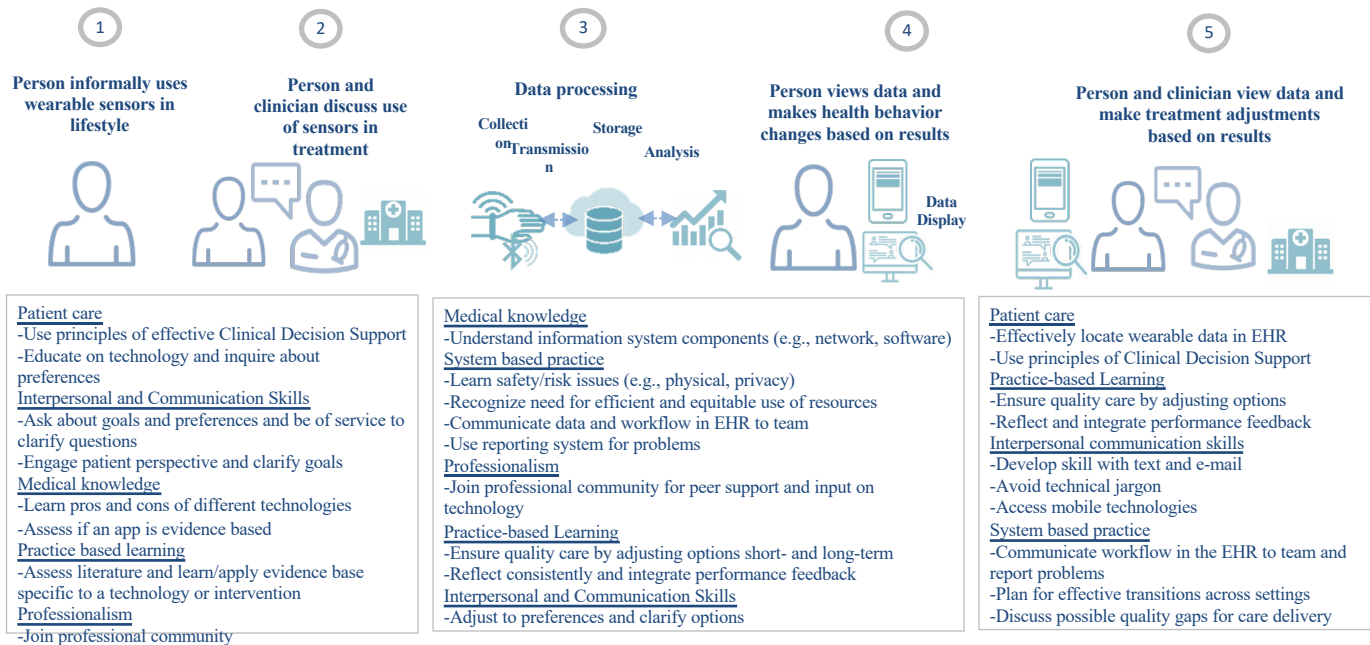
- PGHD is stored in VA's PGHD database which meets all Federal and VA requirements for security and privacy.
- This data is governed by its own Privacy Act System of Records Notice (SORN) "VA Mobile Application Environment (MAE)-VA", 173VA005OP2.
- PGHD is not part of the Veteran's official health record unless a provider actively migrates or pastes adds the data into the electronic health record (EHR).
- Any data that is copied and placed added into the EHR by a provider becomes part of the official VHA health record and subject to all rules associated with the Privacy Act SORN, "Patient Medical Records-VA", 24VA10A7.





# PGHD Competencies Across Workflow

## Applicable Competency Domains Across Clinical Workflow



Hilty, D. M., Armstrong, C. M., Edwards-Stewart, A., Luxton, D. D., Gentry, M. T., & Krupinski, E. A. (accepted). A scoping review of sensors, wearables, and remote monitoring for behavioral health: uses, outcomes, clinical competencies and research directions. *Journal of Technology in Behavioral Science*.



# Recommendations for Providers re: PGHD

VA providers are encouraged to make patients aware of the potential benefits of sharing their PGHD with their care team. This can include:

- Discussing how apps and devices can be used to collect PGHD
- Describing benefits and limitations of PGHD
- Understanding that patients may consider PGHD an important part of their care
- Connecting the patient to designated VA staff members who can offer more information, as needed





# Recommendations in Clinical Care

PGHD is a viable source of clinical data in situations where:

- There is high patient buy-in and patients see clear benefits to tracking data
- Clinicians and care teams are utilizing a holistic approach that lends itself to data from multiple sources
- PGHD will be used to drive decisions within a holistic treatment plan; or in cases where validated specificity and sensitivity are not required
  - e.g. building out a normal baseline of blood pressure to monitor long term changes rather than gather accurate daily readings
  - Examples of use cases include: Whole Health or Mental Health
- Barriers to patient use and syncing data exist, but we are actively working toward breaking down these barriers. Ideally, data should sync automatically or with minimal effort on the patient's behalf





# PGHD Resources

## Using **Patient-Generated Health Data** in VA Care



**Patient-Generated Health Data (PGHD)** enables U.S. Department of Veterans Affairs care teams to offer continuous care to their patients. PGHD gives VA care teams greater insight into patients' health and empowers patients to be more engaged in their care.

**? What Is PGHD?**

PGHD is health-related data that patients and their family members or caregivers create or gather outside of a clinical setting. For example, patients can log health and lifestyle information such as diet, mood, sleep, and weight, or they can use wearable devices and sensors to gather data such as blood pressure, glucose levels, and heart rate. PGHD is distinct from the data generated in clinical settings and through encounters with providers.


**Patients can create or gather PGHD using a variety of tools, including:**

-  Health-related VA Mobile apps, such as Annie App for Veterans, MobileKidney, and My VA Images.
-  Devices that are connected to the Sync My Health Data app, such as accelerometers, glucometers, and smartwatches.
-  My HealtheVet, VA's online patient portal.

**>> As new technologies become available to patients, VA's PGHD database may expand to include additional data sources.**



## Introduction to **Patient-Generated Health Data** for VA Staff



4-Part Video Series  
(for healthcare staff and Veterans)

PGHD Fact Sheet





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# VA Virtual Care Resources

Office of Connected Care Communication  
Toolkits <https://connectedcare.va.gov/outreach-toolkit>

Connected Care Academy  
<https://vaots.blackboard.com>

Connected Care Discussion Series  
<https://mobile.va.gov/discussion-series>

Connected Care Integrated Care Series (email  
[VHA10P8TELEIPT@va.gov](mailto:VHA10P8TELEIPT@va.gov) to be put on  
distribution list)

VA Connected Care Community of Practice (email  
[chimplmentation@va.gov](mailto:chimplmentation@va.gov) to be put on  
distribution list)

My HealtheVet  
<https://myhealth.va.gov>

VA Mobile  
<https://mobile.va.gov/Appstore>  
<https://Tinyurl.com/tech-into-care>



# Thank you!



[www.connectedcare.va.gov](http://www.connectedcare.va.gov)